

From: dalekat5@aol.com
To: Infoc4d@aol.com
Sent: 2/10/2010 4:41:44 P.M. Eastern Standard Time
Subj: Re: from beka- dystonia

I was diagnosed with Spasmodic Torticollis (CD) in 1979 by a Neurologist in New London, Ct. I was one of the lucky patients in that I got the right diagnosis on the first try, He put me on a med and after a month of terrible side effects I weaned myself off the medication. I saw another Neurologist at Yale New Haven Hospital. He talked about a different approach: relaxation exercises and psychotherapy along with meds. So, I quit my job as a Medical Technologist and for the next year did relaxation exercises, rode a stationary bike and went to weekly psychotherapy sessions. I wasn't on any medications. Within 18 months my symptoms were gone.

Twenty four years later in 2003, my head started tipping to the left and I started having pulling and tightness in my neck. I knew my CD was back and it was devastating. I started on meds again and like before weaned myself off of them. I was told about Botox, but the hospital I was going to had at least a year's waiting list for it. So I figured I'd do what I did 23 years before: relaxation, psychotherapy, ride my bike and this time a lot of prayer. After two years I could see some changes but I knew it was time to try Botox. So after we moved from Albuquerque to Gulf Breeze, Florida I found a wonderful and knowledgeable neurologist who had a Dystonia Botox practice. I've been on Botox injections (every 3 months) for 4 1/2 years now.

When I was house-bound in Albuquerque, NM, for two years what kept me going was writing "How Big Are The Pancakes?", the story about my cross-country bike trip. Often times I wondered if I would ever ride a bike again. It was during this time I made a promise to myself that somehow, someday I was going to ride cross-country again. This time for Dystonia Awareness! So the ride I'm embarking on in July 2010 will be a culmination of a six year journey of preparing myself physically, spiritually and emotionally for Cycle For Dystonia, I'm psyched and ready to educate people about Dystonia and give hope to all those who are suffering.

Therapeutic horseback riding sounds awesome. You will definitely inspire many people with Dystonia to try it. Horses are beautiful, sensitive creatures that you can have a special bond with. After this trip I may hang up my two wheel steed and find one with 4 legs. You mentioned riding along the Erie Canal bike path. When the tour arrives in NY State we will follow the Erie Canal bike path from Buffalo to Albany. I grew up in Dansville, NY (south of Rochester, east of Geneseo, NY), so I am familiar with the Erie Canal but have never had the opportunity to ride along it.

My husband Rodge and I are funding the ride ourselves because we want all support and money to go to Dystonia. I would appreciate any pamphlets you may have. My Cycle For Dystonia blog will go live the beginning of June. It will show-case the tour with a route map, my itinerary, info on Dystonia etc, I can send you the link, so people can follow along. Once again, thank you for all you do for so many people.

Tailwinds,

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